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ABSTRACT

A question-and-answer format is used in this fact sheet to provide information on case management for individuals with mental retardation. The fact sheet describes the major components of a case management system, the role of the case manager, the individual's or family's role in case management, providers of case management services and systems for delivering such services, the elements of "best practice" for a case management system, and conditions that inhibit a case manager's effectiveness. (JDD)

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CASE MANAGEMENT FOR INDIVIDUALS WITH MENTAL RETARDATION

What is case management?

Case management is a service families may choose to use when they need help obtaining needed supports for their sons or daughters to live as independently as possible in the community. Case management is defined as "the set of logical steps to assure that individuals receive needed services in a manner that is both supportive and cost-effective." *(University of Minnesota University Affiliated Program, p. 1, 1988.)*

Other terms used to describe case management activities include "service coordination," "service integration" and "client-level service coordination."

What are the major components of a case management system?

Although case management systems vary, they typically include the following components:

- An intake process to determine eligibility;
- A process for matching the eligible individual with a case manager who will gather information about the person's needs and desires;
- A team meeting to develop an individual plan which includes the person being served, the person's family or guardian, representatives of service providing agencies, an advocate or any others the person would like to be on the team;
- Agreements on obtaining services designated in the plan;
- A process for monitoring quality of the services and revising the plan, annually or as needed.

What is the role of the case manager?

Case managers help people with mental retardation and their families identify and obtain needed services. Case managers also advocate for, monitor and evaluate services along with famillies or guardians.

A key role of the case manager is to assist people with the steps and paperwork necessary to obtain services. The system of multiple agencies providing services for people with mental retardation can be complex and confusing. Families often must collect information, fill out forms, make appointments and visit different places before the right service for their family member can be obtained. All of this can be time consuming and frustrating. Good case managers can provide a "single point of entry" into services for the person with mental retardation. A case manager, knowledgeable about the services available in the community, the eligibility requirements and application process, can quickly and efficiently assist the person or family in obtaining needed services.

What is the individual's or family's role in case management?

The person or family or guardian who requests case management assistance holds the ultimate decision-making power throughout the case management process, including:

- Control of entry to and exit from the system;
- Participation in development of the individual plan;
- Veto power over recommendations made during the individual planning process;
- Right to have an advocate present during the planning process;
- Right to decide which services will be procured;
- Right to refuse services as well as to receive services.

Who provides case management services?

Case management may be provided by human service, mental health or developmental disabilities agencies, health care providers, education agencies and frequently by families themselves as described below.

- **Families.** Parents or guardians who arrange for services, therapies, appointments and payments, and manage the home and social dimensions of their child's life are, in fact, serving as case managers. *(Federation for Children with Special Needs, undated.)*
- **Human service, mental health or developmental disabilities agencies.** Case management was established as a process to speed deinstitutionalization. Case management is also viewed as a vital ingredient for supporting a family and community-centered array of integrated and inclusive service options.
- **Health care providers.** Case management refers to activities which organize, coordinate and monitor service delivery to meet the needs of chronically ill individuals and their families.
- **Education agencies.** Case management services are listed in P.L. 99-457, the Education of the Handicapped Act Amendments of 1987, as one of the essential components of a comprehensive system of early intervention programs for infants and toddlers, ages birth to 3.

The functions of case management in these various settings should have the same goal: to ensure that each individual is provided opportunities to achieve maximum development and to live and experience life in a family and as part of the community.

How are case management services provided?

Each individual served has a case manager. Case managers are typically employed by an agency organized to support individuals in obtaining the programmatic and support services which they need and seek. The case management organization should be separate from direct service provision in order to be impartial in negotiating, coordinating and monitoring services for individuals. This is referred to as independent case management.

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What are the elements of "best practice" for a case management system?

- Clear and enforced standards at the state level outlining the responsibilities of case management;
- Implementation of case management at a level closest to the individual;
- Case management program operation by government or private entities that do not directly provide services to reduce conflict of interest in decision-making;
- Case managers with an adequate knowledge base and values orientation to carry out their duties;
- Qualified case managers who receive adequate preservice and inservice training and continuing education;
- Adequate supervision and support for case managers on the job;
- Manageable caseloads which, depending on the factors discussed below, should consist of no more than 30 people per case manager;
- An external process at the state level to monitor and evaluate the quality of case management (with the capacity to provide technical assistance);
- Adequate funding for case management; and
- A system without serious gaps in services. *(Minnesota Governor's Planning Council for Developmental Disabilities, 1988.)*

What are some conditions that inhibit a case manager's effectiveness?

- **Too Large Caseloads.** The chief problem faced by many case managers is their caseloads. Numerous reports have documented this problem and its consequences. Case managers in the United States may have caseloads of more than 100 people, some approaching 300. The states or regions which are considered among the national leaders in community services are those in which case management caseloads are at reasonable levels, and all the elements of good case management are present.

  While a state-by-state survey has not been completed, the Minnesota Governor's Planning Council on Developmental Disabilities has identified the following examples of case load ratios reflecting good practice: Michigan, 1:18 to 1:25; Massachusetts, 1:30; Massachusetts foster care, 1:20; New Hampshire, 1:25 to 1:30; Pennsylvania Pennhurst catchment area, 1:30 *(1988)*.
- **Inadequate Training.** Case managers are often hired who have not been trained. As a result, they might spend more time on paperwork and other tasks (often with less effective outcomes); they might not address problems in a timely fashion, if at all or they might become highly disenchanted with their jobs and quit or seek other assignments. Preservice training should not focus solely on clinical social work but should include community organizing, advocacy and state-of-the-art approaches.
- **Nature of Case load.** Even with proper training, there are circumstances when a case manager can only properly work with 10 to 15 active cases. Some may be able to maintain a case load of about 40 when at least part of their case load is made up of individuals with a limited need for services.

  The nature and level of case management services varies with each individual. A person's disability and its effects on his/her life will be a factor in determining the degree of case management services. There are other factors, including whether an individual has been in a relatively integrated environment all his/her life versus a large segregated setting. The case manager's role might also vary, depending on whether or not the family has good advocacy skills and shares case management responsibilities. All of these factors combine to dictate the size and mix of a case manager's case load. Preservice and inservice training must match the context of the case manager's role.
- **Gaps in Community Services.** In order to be effective, a case manager needs to have access to a wide range of community resources. A 1987 ARC survey revealed extensive waiting lists for community services throughout the United States. More than 63,000 people were waiting for residential services while nearly 76,000 were waiting for daytime programs *(ARC, 1988)*.

  Services must also be appropriate and satisfying for the individual and his/her family and based on value-based principles such as individualization, respect, dignity, freedom from harm, integration (participation), independence (interdependence) and productivity (contribution) *(ARC, Position Statement on Quality, 1989)*. Gaps may exist if available services do not meet these elements of quality.

What is needed for high quality case management to be widely available?

The ARC must join with others to advocate for quality case management services that are fully funded. Family members and people with disabilities should request training about case management and serve as co-case managers whenever possible.

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This fact sheet was prepared with the assistance of ARC's Program Services for Children and Adults Committee: Chairperson, Colleen Wieck, Ph.D.; Mike Remus; Janna Starr; Joan Thompson and Jeri Nelson, M.D.